



Comprehensive Epilepsy Program

Epilepsy Surgery Book

(With patient Testimonies)

Introduction

Surgery is the most definitive treatment for difficult epilepsy, often resulting in a cure. Unfortunately, the fact that surgery is a treatment option for difficult epilepsy is not widely known. Worse, physicians are not always up to date and informed about this topic, and they may at times give their patients inaccurate (and scary) information.

The purpose of this booklet is to help alleviate the fear of patients who are considering surgery, and to correct possible misconceptions.

This booklet features real people who have had surgery at our center. Sometimes there is a testimony by the patient, sometimes a commentary, sometimes both.

All patients featured here have given written permission to use their stories and pictures in order to help others. Most are more than happy to be contacted by telephone to speak in person about their experience. We appreciate their willingness to do this.

As the busiest surgical epilepsy center in Florida, we now perform over 40 surgeries per year, so these are only a few of our patients. To see complete numbers and statistics, and for more information, please contact us or go to our web site at: <http://epilepsy.usf.edu>

Selim R. Benbadis, MD

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Robin

• Our lives turned upside down in July 2007. I woke up in the middle of the night on our bedroom floor as two fireman and my husband stared at me. I was brought to Tampa General Hospital, discovered that I experienced a grand mal seizure and was soon after diagnosed with Epilepsy. The sensations/dizzy spells I had been experiencing throughout the year prior to the grand mal seizure were partial seizures. At the time, I assumed these spells were a result of recovering from having two young children so close in age, along with sleep deprivation, so I didn't think much of them. My gynecologist, and general practitioner, weren't concerned with these sensations, so I wasn't either. "Hormone related", they told me, but I learned the hard way they were incorrect. I was holding our younger son at a store, I felt one of those "auras" that I often felt, but didn't think much of it because they always went away. It started to become a sensation much stronger than usual, so I clutched my son tight and couldn't remember what happened until I woke up to many people looking over me while our son cried his eyes out. My worst nightmare came true in that I had a seizure fainted and fell on our child. I told my husband I couldn't live like this anymore. On December 4, 2008, Dr. Vale performed a right temporal lobectomy. I wasn't sure what to expect with the recovery process, but speaking with others that had been through this provided us with much needed comfort. We can't say enough great things about the staff at Tampa General Hospital and we will be forever grateful to every, single one of them, especially Dr. Benbadis, Dr. Vale and Valerie. I have reached the six month post brain surgery milestone, still seizure free and feeling better then ever. I am excited to finally be able to wean myself off these anti-seizure medications that make me so tired and full of anxiety. Since surgery, I have completed 8 half marathons and am currently training for the Chicago Marathon in October, 2009, which will be just 10 months post surgery.



Melanie

• "I had been an epilepsy patient for 5 years before I was able to consider the possibility of surgery. When I was first diagnosed with epilepsy, I came into contact with various seizure medications and none were able to get rid of my seizures. My seizures started right after I started driver's education before my 16th birthday. I was very upset because my life seemed much more difficult than the lives of my friends. AT least once a week I was having seizures that left me extremely tired and in a state of confusion. It was very discouraging to have to go through most of high school and all of college with epilepsy and its added difficulties. Just before I thought that I would never be able to drive and that my seizures would last forever, I came into contact with Dr. Benbadis.



I learned that surgery was a possibility to cure seizures, and that I should not give up hope for a cure. After being accepted as a candidate for surgery, I knew that the possibilities of being independent and seizure free could be considered again. Since surgery, I have been seizure free, which is quite a change in my life, because I used to have at least one seizure a week. I am really thankful to Dr. Benbadis, Dr. Vale, Kip, Leanne, and all of the nurses and EEG techs who have helped me to get a second chance at a much easier and happier life."

• *Melanie had presented a difficult situation. EEG-video recordings (July 2000) indicated that her seizures originated in the temporal lobe, but the lateral (outer) rather than the mesial (inner most) part. She went through some unpleasant times during her lengthy evaluation, especially since she had convulsive seizures during monitoring, and a difficult time during the Wada test. Furthermore, her MRI showed abnormalities in both temporal lobes. Therefore, she required an invasive EEG evaluation, with electrodes inside the skull. Despite the difficulties, she made the courageous decision to proceed towards possible surgery. The first operation allowed us to pinpoint the area of seizure onset with enough confidence, and finally on May 12, 2001, she had a left temporal lobe resection by Dr. Vale. Since then, she has been completely free of seizures and aura except for one isolated seizure without explanation. Between her first monitoring and her surgery, Melanie worked for several months as a volunteer in the EEG lab and epilepsy monitoring unit, and has become friends with all of us {updated 2009}.*

Debra

• "I cannot express the gratitude I have for Dr. Benbadis and Dr. Vale. For 22 years I had petit mal seizures. At times grand mal, even with the increase of medications I was still having seizures. I had myself convinced that this was the way my life was going to be, and there wasn't anything that could change it. I only drove when it was absolutely necessary such as work. I was driving from work one evening and had a grand mal seizure, I lost consciousness and my car had been submerged in a lake. The following day after seeing my neurologist, he said there wasn't any more that he could do for me. He then told me that he knew of the Epilepsy center in Tampa. Dr. Benbadis told me that he felt that surgery might eliminate my seizures. I had surgery on July 3, 2001, and again January 2003. For the first time in 22 years I am seizure free and I can live a normal life."

• *Debra started having seizures at age 26. Her seizures consisted of staring and unresponsiveness ("complex partial" seizures) sometimes preceded by a déjà vu sensation (aura) and continued several times a week despite several antiepileptic drugs. When she was referred by her neurologist (Dr. Vollbracht, Largo, FL), testing indicated clear left temporal onset. She underwent a left temporal lobectomy (Dr. Vale) on July 3, 2001. She was improved but continued with some seizures, so she*



had a re-operation January 2003, and she has been seizure free since.

Alicia

• "I began having seizures in April of 1999, my sophomore year in high school. I was sixteen years old and had gotten my car just two months prior to the beginning of my battle with epilepsy. I was very scared and went approximately nine months with auras that were easily hidden. Therefore I did not tell family and friends about my problem. This was the biggest regret I have throughout my entire journey. My auras developed into "complex partial" seizures, and my family and friends began to notice. I went to my neurologist, Dr. Zala (Brandon, FL). After trying different medications, he referred me to Dr. Benbadis - the best thing that ever happened to me. I was given a new hope. I was put on another antiepileptic medication that, once again, did not succeed in conquering my seizures. Dr. Benbadis then suggested surgery. At first I was horrified. I had already had four surgeries on my stomach due to another disease as a child, so surgery was not a word I liked to hear. However, due to the comforting words of Leanne, Dr. Benbadis and Dr. Vale, I was not as scared anymore. These are people who know what they are doing, and know how to comfort a patient in emotional distress. Throughout the process of defeating my epilepsy, I had monitoring with EEG testing several times, and eventually my seizures were specifically localized. Although these tests made me scared and frustrated, I stuck with it and never gave up hope, which is the one thing an epileptic patient should always do. The most stressful procedure was the Wada test. My advice to anyone who has to do the same is to not fear this test because it is not as frightening as it seems. I was very scared prior to the procedure, but the actual procedure is not scary, it is not painful, and it does not have negative effects afterwards. Think of it as the next step closer to the defeat of your epilepsy. On July 3rd, 2001, Dr. Vale performed a temporal lobectomy on me. He is an amazing neurosurgeon as Dr. Benbadis is a neurologist, and due to their hard work, I am a healthy and happy person again. Words fall short of expressing how they have affected my life, and in no way could I ever repay them for what they have done for me. "

• *Alicia has been seizure free, off medications, and has become a nurse {updated 2009}.*



Gail

• "When I was a small child, I had febrile convulsions at the age of 2 or 3. They occurred until I was about 3 1/2 years old. They did not reoccur until about 4 years ago when I was going through menopause. Although I was advised to have the temporal lobe lobectomy at Shands Hospital about 4 years ago, I did not take that advice because naturally I was afraid. I strongly recommend the operation to anyone whom Dr. Benbadis and his team of surgeons can perform this



procedure. First, Dr. Benbadis is a doctor who tells you the truth exactly as it will be. This helped alleviate any fears I may have had. He has the gifted ability to inform his patients as to the necessity of the operation and the success of the operation. He has a tremendous support system in his surgeons, in my case Dr. Vale, and his entire office works as a team with excellent results. I strongly urge you to do as I did and listen to his advice as I have been seizure free since the operation December 11, 2001. I feel strong and whole again. After 4 years of seizures which were changing my life, I am thankful that I put my brain in their very capable and caring hands. These are gifted, talented men who can help any epileptic patient. Thank you Dr. Benbadis, Dr. Vale, and staff.”

Roni

• My name is Roni-Kay, and I have been a seizure patient for the past thirty years. As a child, I was very involved in the Epilepsy foundation, being a poster child and attending the summer camp in the Everglades. At that age I was told about all the problems my seizures would cause throughout my life. I took several different medications with good trials and some failures. I started with the initial dose minimum and went to the maximum dose allowed. There were days where I would have one seizure and other where I would have



twenty. After seeing for myself and my family seeing the intensity of my condition, I decided to have the surgery recommended by Dr. Benbadis and Dr. Vale. On April 24, 2008 I had a left temporal lobectomy. It has been one year and since then, I have had no auras, no seizures, and have been able to decrease my medicine on a steady basis. My life has changed. I have never felt as energetic and been on as little medication since I was an infant. There is nothing I would change since I elected to have this. If I may help one other person who is considering this surgery, it is the least I can do for the help that I have been given. I remain seizure free and off all medications for the past one and a half years.

Sarah

• I started having complex partial seizures when I was 20 years old in 2002. I would have a strange déjà vu feeling that I would describe as “getting dizzy” to others around me. Then I would begin wandering around aimlessly asking everyone around me where the bathroom was and babbling nonsensical words. I would always wake up in a bathroom dazed and with no memory of what had happened or how I’d gotten there. Because I didn’t remember having the seizures, I had a hard time believing they were happening and was in denial for at least a year. I had my first grand mal seizure in college. This finally convinced me that I needed to see a doctor. Over a period of 8 years I went to five different neurologists, but none could tell me what was going on in my brain. I had many tell me to go to regular doctors because the episodes might not be seizures. I was told on different occasions that the episodes could be due to blood pressure drops, hypoglycemia, heart problems, sleep deprivation or a poor diet. Finally in graduate school, five years after I started having seizures, a new neurologist agreed that my episodes were complex partial seizures. He tried several combinations of medications, and continued to increase my dosage but still nothing worked. I had a few MRIs and EEGs but the test results were always clean. The reason why I was seizing remained a mystery. Doctors continued to increase my medication dosage but the seizures remained uncontrolled. I’m an opera singer by trade but am not offered health insurance through the opera companies because I am considered self-employed. Therefore I was taking over \$1000.00 worth of medications every month and having to pay for it out of pocket, not to mention the extra expense of neurologists’ appointments and tests. I gave up entirely on having tests done and doctor visits and many times I had grand mal seizures because I couldn’t afford to buy the medication that controlled them. Finally in 2009 one of my many neurologists referred me to Dr. Benbadis. In my first consultation I told him what was happening to me and he told me I was having complex partial seizures of the right temporal lobe. This was the first time a neurologist knew what was wrong with me. I was very excited. He told me I was a prime candidate for surgery. Even though I was going to have to pay for all of it entirely out of my own pocket, I didn’t hesitate. We began the extensive testing immediately. The team at the epilepsy center at Tampa General Hospital was generous and helpful. They even found ways to help me with the costs of the very expensive tests.



I had scheduled the surgery because I knew it was the right thing to do. I was going to be seizure free! Dr. Vale warned me that I would have problems with my jaw because of the incision they would have to make they would have to make through the muscle that controls it. This could possibly make it difficult for me to sing after the surgery. Also, the tubes that are necessary for anesthesia could possibly damage my vocal chords. Even with those risks I knew I had to have the surgery. I had the surgery on January 14th 2010. I am happy to report I haven’t had a single seizure since! I recovered very quickly. I did have a little trouble opening my jaw right after surgery but I was able to sing again in only two weeks. I thank God for using the Epilepsy Center in Tampa General and my opera sponsors to make this possible.

Ursula

- “I feel as if I need to express how grateful and most thankful I am to all of you. You have always been there for me from day one. Had it not been for you, I don’t know where I would be right now. Since my surgery in September 2002, I have been seizure free. Words just can’t express how thankful I am.”

- *Ursula’s seizures were typical complex partial seizures, and were uncontrolled on medications. At one point they had been diagnosed as a heart problem and she received a pacemaker for her “seizures.”*



Troy

- I began having simple partial seizures when I was in grade school. I would be unable to talk for a brief period of time, might have an abnormal movement and would always sense déjà vu. After the seizure I would be exhausted and terrified. I was afraid to let people know what was happening to me because of the embarrassment. I also never could fully explain what was happening and why, to my parents or doctors. I grew up trying to keep it to myself and feeling inadequate. I felt like whatever was happening to me was my fault. Looking back, I feel this led to a lack of self-confidence and self-esteem. I began seeing Dr. Benbadis in, 2003 I was amazed when he told me that there might be a way to correct my problem. I couldn’t believe it. I had never heard this from any other doctor. Honestly, I was rather scared about the whole idea of surgery. I did have multiple EEG’s and various other tests done to determine if I was a candidate, which I was. My seizures began to worsen in 2004. On Thanksgiving Day, 2005, I was driving my future wife to the airport when I had a complex partial seizure. It resulted in a 3 car crash. I am so thankful that no one was seriously hurt. The next week I called Dr. Benbadis’ office and said I was convinced surgery was what I needed. On Valentine’s Day, 2006, I received a left temporal lobectomy. The first week after surgery, I still had seizures but they were secondary to recovery. Three weeks later, I returned to my job and I haven’t had seizure in 3½ years. I am now beginning to decrease my medication. The only side effects from the surgery are that I sometimes can’t think of words mid-sentence. I may not be able to think of the word or I may get names mixed up. If I give myself a second or picture something in my head, I always get the word. I can’t put in words how grateful I am to everyone that was



involved in my care. I used to feel that the fear of seizures would always hang over me. It doesn't anymore. I feel like a new person. I feel better about myself now than I ever did. I have a true purpose in life and I can accomplish it. What a great feeling.

Jorge

• I was first diagnosed with a seizure disorder in 1984, at age 14. I suffered from grand mal, petit mal, and complex partial seizures. Since then, I have been on a total of eight medications, up to three at a time. On October 31, 1997, I had a seizure while driving on a local highway, swerved into oncoming traffic and hit a full sized pickup head on. I fractured my right hip, both wrists and had a concussion. I had seen a total of five different neurologists, faced the fact that I would be on medication and having seizures for the rest of my life. My local neurologist thought I should be referred to Dr. Benbadis to see if I was a candidate for surgery. After all that had already happened, I didn't hesitate to say yes. I was hopeful, but didn't get my hopes up much for it to be successful after all the failures from the medications in the previous 24 years. On August 21, 2008, I had my surgery a right temporal lobe resection. I was discharged on Sunday, August 24. I missed less than a month of work (returned to work on September 17). The only effects I suffered from the surgery were minimal, difficulty opening my mouth, which Dr. Vale had informed me prior to the surgery. In August, 2009, I flew to Europe to visit family, with no effects from the surgery. On October 27, 2009, just before the 12th anniversary of my accident, I received my driver's license. Then on November 15, I once again own a car and no longer have to depend on others for transportation anywhere. My family has told me that they have also noticed a difference in my personality, for the better.

